Voices of Youth and Families on Living a Successful Life in the Community

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In recent years, mental health researchers and service providers have become increasingly concerned about the challenges facing young people with mental health needs as they transition from high school to college or work. In addition to the developmental challenges facing all young people as they move from adolescence into young adulthood, these young people must negotiate the transition from receiving mental health services from the child- and family-serving system to the adult-serving system. To date there has been little research on these challenges and the supports that transition-age youth use to become integrated into their communities. This presentation focused on preliminary findings of focus groups designed to explore the perspectives of youth (aged 17-24) and families on community integration of young people with mental health needs.

Literature review

Community integration is defined as the right of youth and adults with mental disorders to live in the community; to have opportunities to live, study, work, and have recreation with other people; to have a sense of belonging in the psychological or social sense; and to have a sense of empowerment and control in making one's own decisions (Prince & Prince, 2000; Nelson, Lord, & Ochocka, 2001; NIDRR, 1999). While community integration of young people with mental health needs has not been an explicit focus of research, there is evidence that community integration is negatively affected by stigma, poorly coordinated and inappropriate services, and lack of transition planning (Delman & Jones, 2002; Lehman, Clark, Bullis, Rinkin, & Castellanos, 2002; Vander Stoep, Davis, & Collins, 2000; Federation of Families for Children's Mental Health, 2001).

While many young people with mental health difficulties face formidable challenges, others have described their successful search for meaning, vocation, and a sense of belonging (Handler, 1998; Simon, 2002). In adulthood, families can be a significant source of support in transitions to recovery (Hatter, Williford, & Dickens, 2000), and some model youth transition programs are achieving successful outcomes using principles of person-centered planning, comprehensiveness, coordination, unconditional commitment, and skill-building to guide their services (Clark, Deschennes, & Jones, 2000). This literature provides a beginning understanding of the issues to be addressed in transitions, but there is no research that specifically examines community integration from the perspective of transition-age youth.

Research focus

The purpose of this study was to gain understanding of the perspectives of youth and young adults (aged 17-24) with mental health needs and family members on the meaning of community integration for transition-age youth. This presentation focused on preliminary findings related to young people's and families' perspectives on the meaning of a successful life in the community; community connections and activities; goals; experiences of social, psychological, cultural, and economic barriers to community integration; supports for community integration; experiences with professionals in the transition-planning process; and advice to other young people and family members.

Methods

After conducting a review of relevant literature, we formed parallel research teams in Portland and Seattle and developed advisory groups of youth/young adults aged 17-24 and family members. We consulted with the advisory groups to develop focus group questions and to plan recruitment strategies for focus group participants. In line with our participatory research approach (Turnbull, Friesen, & Ramirez, 1998), we recruited, hired, and trained a youth research assistant and family member research assistant for each of the two teams.

Data collection. After gaining approval of the project from the Portland State University Human Subjects Research Review Committee, we made contacts with schools, colleges, family support organizations, and mental health agencies to request their assistance in recruiting both young adults aged 17-24 and family members to participate in 90-minute focus groups. Each participant attended one focus group with two or three other young people or family members and completed a pre-focus group questionnaire. Participants received $30 and refreshments during the meeting. In each youth focus group, the youth research assistant took a lead role as moderator, while a project leader played a supporting role as co-moderator and note-taker. Similarly, the family research assistant acted as lead moderator for family member focus groups. Youth and family focus groups had parallel questions for young people and family members. At the time of the conference presentation we had completed and audio-taped seven focus groups (out of our planned 20 focus groups). We transcribed the tapes and completed a preliminary analysis of major themes for presentation at the conference.

Sample description. In the conference presentation, we reported on findings from youth focus groups with 10 young men and 8 young women, with an age range of 16-24; one participant was subsequently discovered to be 28 and his data was included because he was still dealing with transition issues. The racial composition of the youth/young adult participants was five African-Americans, four Caucasian, three multi-racial, one Asian-American, and one African; two declined to answer this question. Eight participants reported living in their own home, five with parent(s), six with roommates, three with a spouse or fiancée, and one alone; one person reported being homeless. Five young people declined to provide their mental health diagnoses; others indicated varied diagnoses, including depression (six); bipolar disorder (three); anxiety disorder (two); and attention-and deficit hyperactivity disorder (ADHD) (one).

Family participants were seven Caucasian females, aged 35-59. Their children were described as five males and two females, aged 17-22. Three of the young people were described as living in their own home, two with parents, one in student housing, and one in a group home. Mental health diagnoses of their youth were varied, including: ADHD (n=4); depression (n=3) anxiety disorder (n=2); post traumatic stress disorder (n=3); attachment disorder (n=1); bipolar disorder (n=1); emotional disorder (n=1); fetal alcohol syndrome or effect (n=1); obsessive-compulsive disorder (n=1); oppositional-defiant disorder (n=1); alcohol and drug dependence/abuse (n=1); and schizo-affective disorder (n=1).

Findings

The presentation reports the preliminary findings from youth, young adult, and family participants for each focus group question.

The meaning of a successful life in the community. Youth responses to this question focused on the importance of opportunities to meet their goals related to school and jobs, relationships and connections with family and other people, and access to resources and support. Family members emphasized the need for young people to develop a sense of independence that includes finding and keeping a job, feeling a part of the neighborhood, taking classes, and time management. One parent defined a successful life in the community in terms of having "self-esteem and confidence that is reflected in profitable work, creative outlets, and real friendships." Other parents focused on developing social and communication skills, participating in healthy relationships, and being able to advocate for oneself.

Community connections and activities. While many of these young people mentioned feeling isolated socially, they described a variety of social connections and activities, including spending time with friends from work and spending time at church, 12-step programs, and at recreational venues such as basketball courts. Health N' Action, a Seattle youth social service program which assisted us with focus group recruitment, was described as an important source of community connection and as, "one of my family, actually… a good part of my life." Parents mentioned support groups and parent education resources as sources of information to increase community connections. They emphasized the need for young people to have opportunities to develop their skills and talents through independent activities and attending college, and through using community resources. For example, parents described local artists who provided support for individual talents and facilitated recognition for youth's abilities. A mother talked about her daughter's musical talent and the recognition she had received for public performances, while another lamented that her son's talents were under-developed at a group home he lived in: "My son loves to cook! He has been forbidden to cook though… It is a real source of frustration for him and myself!"

Three year goals. In response to a question about their goals, most young people referred to career goals. Others wanted new opportunities, and a sense of accomplishment. One young woman saw work as an effective strategy for dealing with her mental health needs:

> *I envision my life being pretty much a workaholic. I dream of living in my office, because I don't like socializing. It is not what makes me happy. It makes me stressed out and nervous, so I would rather just do a whole lot of work, because I am good at that.*

In three years, parents hoped to have their children functioning well, managing their challenges, having contentment, having their talents identified and nurtured, working, taking classes, and living independently. One parent identified her goal for her child as "A job that matches their abilities and ambitions." Another noted, "We have to have hope."

Barriers to community integration. Youth and young adults described barriers to community integration such as stigma, the culture of high school and shortcomings of the educational system, the lack of accessible, and developmentally appropriate resources, and professionals who were uncaring and unhelpful. Young people described incidents where they had experienced rejection by others to whom

they had confided their diagnosis. For example, a young man commented, “I lost a lot of friends once I did try to share it. It was devastating, because one of my friends…was scared that I may go off the deep end. He didn’t want to get sucked into that.” A young woman said, “Now I don’t tell people as often, because I think, one, the stigma. I’m afraid that I will be judged.”

The high school culture was perceived as problematic for youth with mental health needs. A young woman noted, “high school, it was such a huge part of your life, and if that is ignoring your mental health problems, then it is harder to deal with.” The lack of accessible services was a concern, illustrated by the following comment: “They gave me like a list, and there was no one to call and nothing online.” Young people resented incompetent professionals; for example, one young woman commented, “Psychiatrists, I saw a lot, and you know, they kind of messed with me for awhile, because I was on the wrong meds and I was zoned for a year…I was given the wrong diagnosis and the wrong meds.”

Parents mentioned their own and teachers’ lack of information as a barrier to community integration. The stigmatizing effect of having to label oneself as disabled in order to access services was seen as a deterrent to using those services; for example, the Office of Student Disability Services. Parents also reported problems with transitions from residential treatment to large, over-stimulating high school environments. Finally, a parent found confidentiality rules at a residential treatment center, which prevented youth from having contact with each other after they left, as a barrier. The parent felt that contact would have been supportive to her child’s integration into the community.

Supports for community integration. In contrast to their descriptions of barriers to community integration, young people and parents also reported many supports and positive experiences. Friends and family, including grandparents, were mentioned frequently. Gaining awareness of others living successfully with mental health difficulties was helpful, as noted by one young woman: “It was an awesome feeling that this is a thing that other people experience…After that I kind of got to the point where I just tell everyone.” Caring, thoughtful professionals and mentors were also appreciated. For example, one young woman spoke of her high school counselor as “…my best support…She was always there, she was really accessible.”

Factual information about mental illness and mental health was described as useful, as noted by a young woman: “I took a psychology class in high school and that like totally opened up everything…I remember reading the OCD (obsessive-compulsive disorder) section of the book, and I was, Oh my God, everything in here is exactly me.” Information also provided encouragement and fostered hope to another young woman, who reported, “They gave me this list of ten coping skills…They were giving me a way out, or at least something to believe in.”

In regard to supports for community integration, parents commented on the importance of college course work and jobs offering interest, support, and socialization. Individual counseling and therapy and family therapy were also valued. Parents expressed appreciation for professionals who showed a particular interest in their children. For example, a mother said:

> *“A teacher at the community college took a great interest in my son. He recognized his abilities and let him use the resources and equipment above and beyond just what they were doing in these… classes.” These parents said that their work as advocates had been instrumental in getting their children’s needs met. As one parent put it, “There are a lot of therapists out there, but I think as a parent you really have to do a lot of searching yourself, because it is not like anybody else is going to do that for you.”*

Best and worst experiences working with professionals. Supportive exchanges with high school teachers and college professors were cited by several youth as being helpful, especially professionals who listened, were thoughtful in their approach, had a sense of humor and, above all, were caring. Family members mentioned their appreciation of responsive teachers, residential treatment providers who

helped them to identify and connect with follow-up services, and therapists who inquired about their well-being and validated their experiences.

Youth reports of worst experiences were focused on professionals who seemed to be just "concerned about picking up a paycheck" or were too formal and overly clinical. Families' worst experiences were frequently mentioned as occurring in public schools. For example, one mother commented:

> *80% of my experiences with IEP meetings were horrific… it was that principal who just thought everybody was just faking. And then her side kick, the psychologist, who says "Well, your expectations are too high. A "C" average is just fine. You don't need to go to college.*

Another parent described feeling outraged when a child welfare staff member "tried to deceive us to get custody when we asked for help with funding for her residential treatment."

Advice to other young people and family members. When asked what advice they would give to other transition-age youth, these young people recommended finding support people who have had similar experiences and can relate on a personal level. Others emphasized keeping a positive attitude, being hopeful, listening to success stories, seeking information, working hard, and going to school. One young person concluded: "Keep your head up. Do what your heart tells you."

Family members advised other parents to get personal counseling for themselves and join groups like NAMI (the National Alliance for the Mentally Ill) "to get ideas, feel safe, and develop a big social network." Other suggestions from parents were to get enough sleep, to call friends for help with tasks like cleaning house, and to gain as much information as possible about mental health issues. Finally, parents noted the challenges of letting their children grow up while worrying about their well-being, exemplified by one mother's comment that: "Your child has to learn to be their own person. It's really, really hard when you see them in dangerous areas… you have to trust in your child's own strength."

Conclusions and implications

At this preliminary stage in the study, it would be premature to draw conclusions and our qualitative methodology does not permit us to generalize from our findings. Nevertheless, we feel justified in concluding that for all of the youth and young adult participants in this study, the transition from high school to adult life has been difficult and, for some, a successful life in the community is still an elusive idea. For some youth, the absence of support from family and friends has left them struggling, while others have appreciated the support of parents, teachers, mentors, caring professionals, and friends. The parent participants have been challenged to support their children to achieve their preferred level of independence. Common themes among both young people and parents in this study were the need for connections with others who are experiencing (or have experienced) similar challenges, accurate information about their mental health difficulties, and the importance of hope.

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